What is expected of me before and during a genetics visit?

- Collect and share information about your family and health history
- Try to obtain medical records on affected family members (as directed by clinic staff)
- Write down your questions and bring them to your appointment
- Ask questions about the care or treatment you or a loved one is receiving
- Ask your genetic care provider to explain anything you do not understand
- Help your genetics team by talking about any change in symptoms or health status, no matter how small
- Express your personal, cultural beliefs
- · Make informed personal decisions



What about genetics and privacy issues?

It's good to know that **Michigan Law** protects the privacy of genetic information and patient rights when undergoing genetic counseling and testing. For more information about informed consent for genetic testing, visit the website or contact the Michigan Department of Community Health at the numbers listed below.

Where can I find more information?

Visit <u>www. MiGeneticsConnection.org</u> or call the Genetics Information Line toll-free at **1-866-852-1247**. The direct number is (517) 335-8887. You can also e-mail questions about genetic services to genetics@michigan.gov.



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www.michigan.gov/mdch

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A Guide for Families and Professionals

oncerns about health or development may arise at any age. When problems occur, family members often wonder about:

- the cause
- the impact on one's life
- other related health issues
- risks to family members
- where to find information
- where to find support

Genetic services may help answer some of these questions. Genetic counseling is the process of giving families information and support on a variety of conditions. These conditions include developmental delay, birth defects, genetic disorders and adult-onset chronic diseases. A genetic evaluation may be done to find a reason for a family member's physical difference, developmental delay or health problem.

What can genetic services offer?

Evaluation

- · Diagnosis of a condition
- Possible cause for developmental delay, behavioral problems or physical differences
- Risk assessment
- Testing

Information

- Facts about the condition and what to expect
- Available management or treatments
- Recent genetic discoveries and current research

Referrals and Support

- Medical specialists
- · Community resources and support groups
- Understanding of cultural beliefs and personal choices

What types of genetic services are available?

Reproductive Genetic Services

Learn about:

- · Birth defects prevention
- · Maternal serum screening
- Prenatal diagnosis (ultrasound, amniocentesis, CVS)
- Risks based on family history
- · Exposures during pregnancy
- · Fetal surgery/treatments if available

Receive:

• Support, resources, and testing if available

Pediatric Genetic Services

Learn about:

- Possible reasons for your child's physical differences, developmental delays, or behavioral problems
- Management for your child's medical or genetic condition

Receive:

- Physical examination
- Support, resources, and testing if available

Adult Genetic Services

Learn about:

- · Living with a genetic condition in adulthood
- Genetic factors in chronic diseases (cancer, diabetes, heart disease, neurological disorders)
- Risk for a condition based on your family and personal history

Receive:

- Possible physical examination
- Screening if available
- Risk reduction strategies
- Support, resources, and testing if available

Clinic Locations

Some genetics centers also provide services at satellite locations within their own health systems.

ANN ARBOR

 University of Michigan Breast & Ovarian Cancer Risk

Evaluation (734) 764-0107 Cancer Genetics (734) 647-8906 Medical Genetics (adult) (734) 763-2532

Neurogenetic Disorders (all ages)

(734) 936-3087 Ophthalmic Genetics (734) 936-8638 or 7384 Pediatric Genetics (734) 764-0579

Perinatal Assessment Center (734) 763-4264

DEARBORN

Oakwood Hospital
 Clinical Cytogenetics (313) 593-8483
 (cancer genetic counseling & prenatal diagnosis)

DETROIT

 Detroit Medical Center/Wayne State University Children's Hospital-

Genetics & Metabolism (313) 745-4513

Hutzel Hospital-

Reproductive Genetics (313) 745-7066

Barbara Ann Karmanos Cancer Institute-

Cancer Genetic Counseling (313) 966-7780

University Health Center-

Charcot-Marie-Tooth Disease (313) 577-1689

Neurogenetics (adult) (313) 577-1689

Henry Ford Hospital

Dept. of Medical Genetics (313) 916-3188 (children, adults & prenatal diagnosis)

EAST LANSING

Michigan State University
 Clinical Genetics (517) 353-2030
 (children, adults & prenatal diagnosis)

GRAND RAPIDS

Spectrum Health
 Genetic Services (616) 391-2700
 (children, adults & prenatal diagnosis)

KALAMAZOO

• Bronson Methodist Hospital Perinatology (269) 341-7887

ROYAL OAK

William Beaumont Hospital
 Div. of Genetics (children)
 Reproductive Genetics
 (248) 551-0487

TRAVERSE CITY

Munson Medical Center
 Reproductive Genetics (231) 935-5500

Outreach Sites

Genetic services for children and adults are available at most of these outreach sites.

Bay City, Midland, Port Huron, Saginaw Henry Ford Hospital (313) 916-3188

Big Rapids

Spectrum Health (616) 391-2700

Flint, Kalamazoo

Michigan State University (517) 353-2030

Gaylord, Marquette, Traverse City

University of Michigan (734) 764-0579

Midland (Cancer Genetic Counseling only)

Mid MI Med. Center/MSU (989) 837-9070

The Michigan Department of Community Health helps assure the availability of genetic services statewide by providing partial support to some genetic centers and outreach clinics.

Where do I go for genetic services?

University medical centers as well as several large hospitals offer genetic services. Outreach clinics are also held at sites throughout the state. Contact the nearest clinic to learn more about the services available to you and your family.

How do I make an appointment?

Talk to your health care provider about your interest in genetic services. You or your provider can call a genetics center to make an appointment. The staff will provide further information to prepare you for your visit.

What is the cost of genetic services?

Each genetics center has a range of fees for consultation and laboratory tests. Services may be covered by third-party insurance. Genetic evaluation and counseling are covered services if your child is enrolled in Children's Special Health Care Services. Financial help may be available for those without insurance based on individual family need. Your family may also qualify for a research protocol covering genetic testing.

